

**FORUM OF ESRD NETWORKS
TESTIMONY FOR SENATE SPECIAL COMMITTEE ON AGING**

**PRESENTED BY JAY WISH, MD
PRESIDENT**

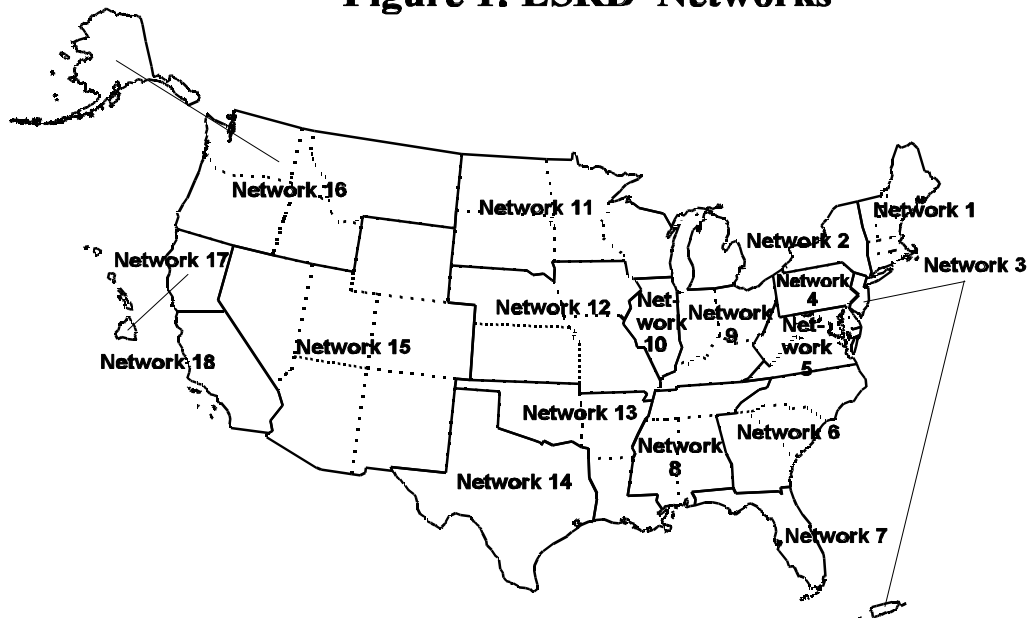
Introduction

The Forum of ESRD Networks (Forum) appreciates the opportunity to testify before the Senate Special Committee on Aging regarding the oversight of Medicare's End-Stage Renal Disease (ESRD) Program.

The Forum is an organization representing all 18 ESRD Networks. The Forum facilitates the exchange of information and ideas among the 18 Networks, renal related organizations and the Health Care Financing Administration and serves as a clearinghouse for the distribution of material to support the improvement of care delivered to patients with ESRD.

The 18 ESRD Networks are independent non-profit corporations established to oversee the quality of care provided to Medicare ESRD beneficiaries. The Networks' contract with HCFA is defined by the scope of work, which specifies activities in quality improvement, data collection/analysis and community outreach. The geographical boundaries of the Networks were re-configured by HCFA in 1988 and are illustrated in Figure 1 below.

Figure 1: ESRD Networks



The Forum is pleased to provide the following responses to questions posed by Senators Grassley and Breaux.

1. Description of the Forum of ESRD Networks

The Forum is incorporated as a 403C non-profit corporation in the state of New York. The bylaws of the Forum specify that the purpose of the corporation is to “serve as a forum in which assistance, advice, information, ideas, and policy proposals may be exchanged between and among the Networks and the Health Care Financing Administration (HCFA) and its agencies, and other renal care organizations.” In 1995, HCFA recognized the value of the Forum of ESRD Networks in providing a clearinghouse for information with relevance to Network quality oversight activities, evolving practice guidelines, patient educational materials, and Federal legislative/regulatory changes which impact the ESRD program. As a result, HCFA provided funds to create the Forum of ESRD Networks Clearinghouse as a support office and information distribution center for the ESRD program. The Forum Clearinghouse office, located in Midlothian, Virginia has acted as a liaison between the Networks, HCFA, and prominent renal organizations and works to facilitate an improvement in the care received by ESRD patients by supporting Network data collection/analysis and quality improvement activities. The Forum office currently consists of one full-time administrator and one part-time assistant. As part of its clearinghouse activity, the Forum office:

- Maintains a web site on the Internet that outlines Forum activities and provides links to the 18 individual Networks as well as to other renal web sites;
- Provides an annual report summary of the 18 individual Network annual reports;
- Provides support to the national ESRD Clinical Performance Measures (CPM) Project;
- Maintains a library of resources to support Network activities including practice guidelines, patient educational materials, nephrology journals, and materials from other renal professional and patient organizations.

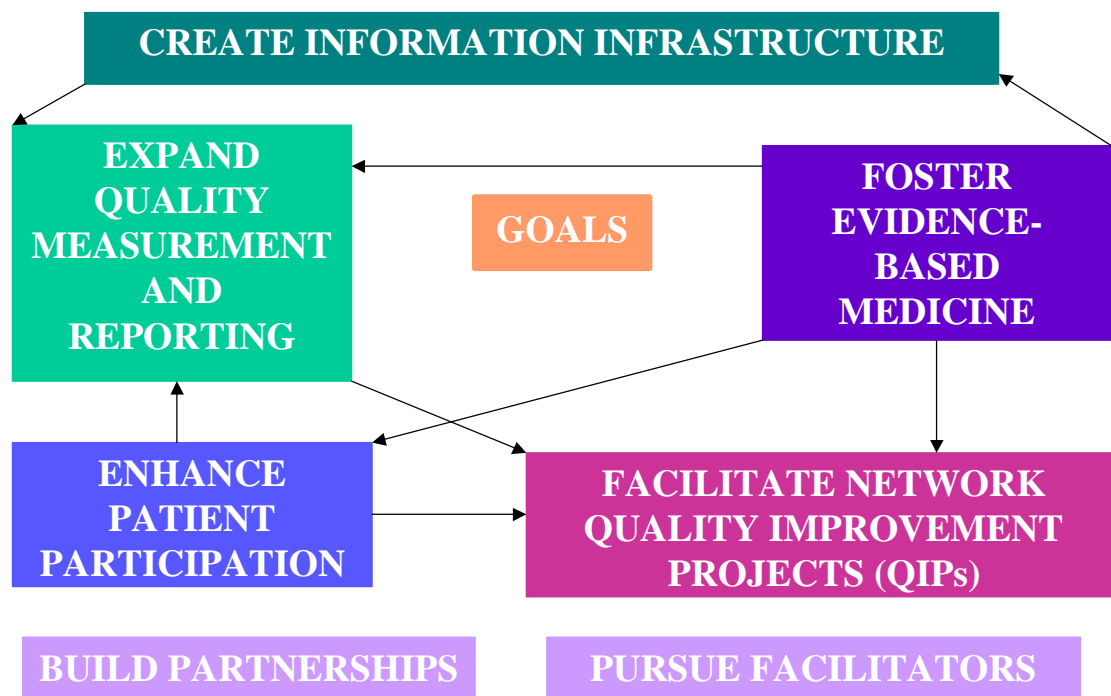
By obtaining consensus on issues of importance to the quality of care of ESRD beneficiaries, the Forum is able to effectively represent the ESRD Networks. The Forum's membership consists of one physician representative, the Medical Review Board chairperson, and the Executive Director from each ESRD Network organization.

The Forum's goals are:

- To foster the improved delivery of care to Medicare ESRD beneficiaries through the Networks' comprehensive quality improvement program;
- To create and maintain an information infrastructure that supports quality improvement activities at the provider level;
- To assist Networks in identifying the areas where the greatest opportunities for improvement exist so that interventions can be most effectively targeted;
- To promote the use of the evolving information infrastructure to accumulate evidence that can be used as a basis for clinical practice guidelines.

These goals are supported by a strategic plan designed to promote a quality measurement and reporting agenda (Figure 2).

Figure 2: Forum Strategic Plan



The Standardized Information Management System (SIMS), a national information infrastructure that supports Network quality improvement activities, was implemented this year (2000). Designed by the Networks, the renal community and HCFA, SIMS was designed to:

- Electronically link all 18 ESRD Networks with HCFA;
- Transfer ESRD data collection forms electronically to HCFA central office;
- Provide standard data elements, data definitions and reporting/analysis tools.

The Forum actively promotes continuous quality improvement activities among the Networks to facilitate outcomes improvement within dialysis facilities and renal transplant centers. The Forum partnered with HCFA to increase hematocrit levels for ESRD patients in the National Anemia Cooperative Project. This project improved the processes of anemia management by:

- Providing facilities with a continuous quality improvement manual with a focus on anemia management;
- Providing facilities with an algorithm for the treatment of anemia;
- Providing facilities with their respective facility-specific profiles on hematocrit and erythropoietin usage.

The Forum was awarded a contract by HCFA in 1999 to develop and administer the national ESRD CPM Project. This project began in 1992 as the Core Indicators Project and involves the annual collection by the Networks of clinical data from a random sample of ESRD patients to assess patterns of care. In 1998, following the publication of the National Kidney Foundation's Dialysis Outcomes Quality Initiative (DOQI) clinical practice guidelines, evidence-based clinical performance measures were derived and provided the basis for the evolution from the Core Indicators Project to the ESRD CPM Project. The CPMs currently used include adequacy of dialysis, anemia management, nutrition, vascular access for

hemodialysis patients, and hypertension management for peritoneal dialysis patients. The annual data feedback reports obtained from these projects are important tools in assessing patient care processes and outcomes on a national and regional level and identifying opportunities for improvement.

2. Description Of Mechanisms By Which Networks Ensure Quality Of Care

The 18 ESRD Networks work directly with ESRD providers to improve the quality of care provided to ESRD beneficiaries. The ESRD Networks do not provide direct patient care. With volunteer leadership by nephrologists, transplant surgeons, nurses, social workers, dietitians, administrators and patients, Networks engage providers to improve patient care processes and outcomes through a non-punitive paradigm. By collecting and analyzing process and outcomes data, Networks collaborate with providers to identify opportunities for improved care and to design measurable quality improvement initiatives. Strict conflict of interest rules apply to assure an objective and impartial review process.

A Board of Directors that provides oversight of Network operations and assures compliance with contractual requirements governs each Network. Each Network has a Medical Review Board (MRB), a multidisciplinary group that directs its quality improvement efforts. All Networks have a structured mechanism to assure patient input and involvement. Patients are represented on the Networks' Boards of Directors and Medical Review Boards.

The current system of external oversight of the ESRD program includes the Networks and state survey agencies. The state survey agencies operate in a regulatory mode to hold providers accountable to the minimum standards mandated by the Conditions of Coverage. The Networks, through their governance by professionals who are associated with individual providers, have expertise on dialysis treatment that the state survey agencies lack. The Networks' collegial orientation stresses education and improvement objectives rather than enforcement of minimum standards.

Through an information infrastructure that has developed over 20 years, the Networks are able to identify clinical trends at the provider, region, state, and Network level and to develop and implement targeted interventions to effectively improve care.

Networks have established channels for coordinating and collaborating with other agencies and organizations to avoid duplication of efforts and to build upon the expertise of many groups. These include HCFA, State Health Department and Survey Agencies, Peer Review Organizations and renal related professional groups such as the Renal Physicians Association (RPA), American Society of Nephrology (ASN), National Renal Administrators Association (NRAA), American Nephrology Nurses Association (ANNA), National Kidney Foundation (NKF), and American Association of Kidney Patients (AAKP).

3. Description Of Relationship Between Networks And Facilities

Medicare regulations require that a Network-facility relationship exist and that all Medicare certified providers participate in Network activities. These relationships are maintained, enhanced and supported by a mutual interest to improve care and assure quality. Each Network interacts with facilities in several ways:

- ! Providing quality oversight;
- ! Implementing facility-specific quality improvement projects;
- ! Sharing facility specific data and regional comparatives with the respective facilities;
- ! Acting as a clearinghouse for information and resources;
- ! Conducting educational seminars and regional meetings.

Although Networks have traditionally assumed a quality improvement role, working in a confidential relationship with providers to educate and improve outcomes through a systems focus, occasionally a provider will not respond to a collegial Network approach. In such cases, a Network may assume more of a quality assurance role by conducting a site visit, requiring a plan for corrective action, referring the problem(s) to the state survey agency, and/or recommending to HCFA that sanctions be imposed.

4. Description Of Processes The Networks Undertake To Ensure That Facilities Are Providing Proper Care.

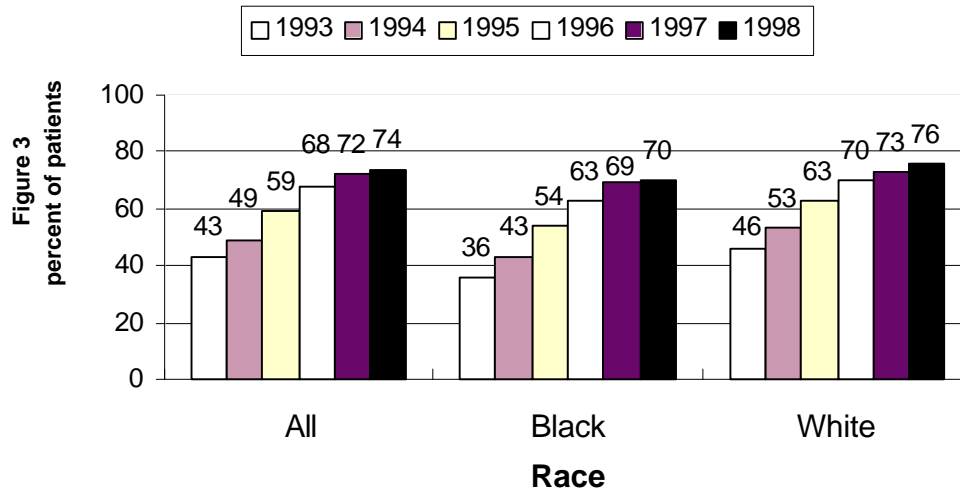
Networks perform specific activities to facilitate the improvement of patient care processes and outcomes at the facility level. These include, but are not limited to:

- ! Participating in the national ESRD Clinical Performance Measures Project;
 - ☐ Raises level of awareness by facilities of measure domains and outcomes
 - ☐ Provides benchmarks of performance that facilities can use as targets
- Conducting focused quality improvement projects and special studies;
 - ☐ Addresses regional variations in processes and opportunities for improvement
 - ☐ Engages expertise of Medical Review Board regarding evidence-based methods
- Managing information and providing profile reports;
 - ☐ Drives internal quality improvement activities at the facility level
 - ☐ Identifies areas for targeted intervention
- Processing patient grievances and addressing patient concerns;
 - ☐ Fosters communication between patients and providers
 - ☐ Mediates conflicts to achieve satisfactory resolutions for patients and providers
 - ☐ Identifies patterns of care which may require intervention activities
- Conducting educational activities including seminars, workshops, newsletters, videotapes, and distribution of printed materials.

The Network program has fostered a national improvement in the four areas of care monitored by the national ESRD CPM Project (adequacy of dialysis, anemia management, hypertension, nutrition). Due to Networks' participation since the project's inception, national and Network specific data are available on care provided to ESRD patients. Over the last 6 years, the CPM project has demonstrated statistically significant improvements in clinical outcomes, likely attributable to Network quality improvement activities. Areas most improved include:

- Hemodialysis Adequacy (Figure 3):
 - ☐ 74% of hemodialysis patients had a mean URR \geq 65% in 1998 compared to 43% in 1993.
 - ☐ The difference between Caucasian and African-American patients receiving adequate dialysis was 6% in 1998 compared to 10% in 1993.

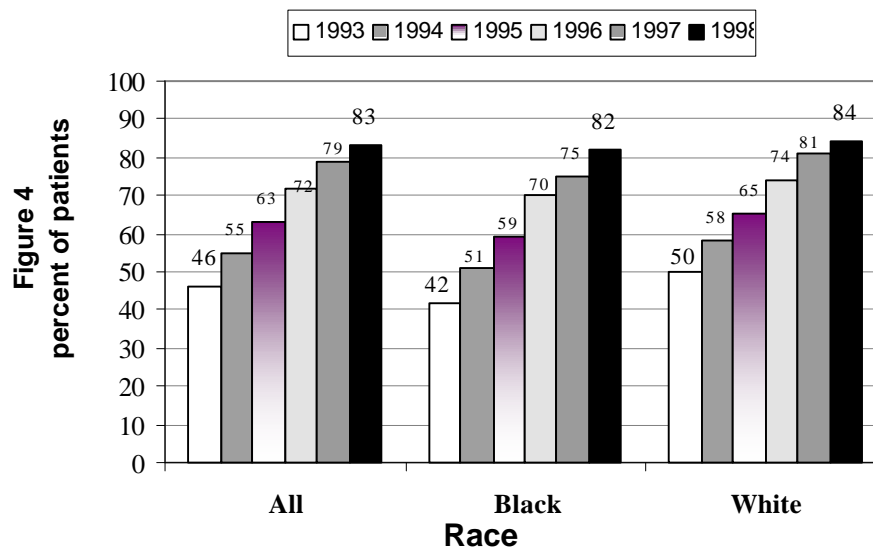
Percent of adult (aged ≥ 18 yrs) in-center hemodialysis patients with mean URR $\geq 65\%$ in Oct-Dec 1998 compared to previous study years, by race, 1999 ESRD Clinical Performance Measures Project



Anemia Management (Figure 4):

- 78% of hemodialysis patients had a mean hematocrit $> 30\%$ in 1998 compared to 46% in 1993.
- The difference between Caucasian and African-American patients with hematocrit $> 30\%$ was 2% in 1998 compared to 8% in 1993.

Percent of adult (aged ≥ 18 yrs) in-center hemodialysis patients with mean hematocrit $> 30\%$ in Oct-Dec 1998 compared to previous study years, by race



These changes demonstrate the positive effects of the partnership between Network and facility staff on the care received by ESRD patients.

Networks conduct quality improvement projects (QIPs) to assess and improve the outcomes of care. QIPs are a continuous process, using data on processes and outcomes of care to recognize opportunities to improve care and to develop measurable improvement initiatives. Examples of Network quality improvement projects include:

- Improving influenza and hepatitis B vaccination rates;
- Increasing the placement of arteriovenous fistulae in hemodialysis patients;
- Improving surveillance for stenosis of arteriovenous grafts;
- Improving adequacy of hemodialysis;
- Increasing the frequency of measurement of peritoneal dialysis adequacy;
- Improving anemia management.

Working one-on-one with Network quality improvement staff and Medical Review Board experts allows the facility staff to improve the care delivered to patients. The Networks are able to achieve buy-in from facilities which understand that:

- Network staff are trained in the principles and application of continuous quality improvement (CQI);
- Network Medical Review Board members are highly respected practitioners with considerable clinical experience;
- Network's data infrastructure offers facilities data tracking tools that they may not otherwise have;
- Networks recognize and praise high performers.

Each Network collects data from dialysis facilities regarding patient demographics, co-morbid conditions, process and outcome indicators, patient events and deaths, and facility characteristics. These data are validated and analyzed by the Medical Review Board and can be used to improve patient care by:

- Supporting facility quality improvement projects;
- Targeting facilities for Network intervention activities;
- Evaluating Network-wide quality improvement projects;
- Driving the development of health care policy specific to ESRD;
- Identifying predictors of morbidity and mortality;
- Entering the medical literature to become part of the evidence basis for the development or updating of clinical practice guidelines.

Networks also provide community outreach services to renal professionals, patients and family members. Using a variety of educational venues and information distribution methods, Networks impact the lives of patients by:

- Conducting patient-focused seminars and conferences;
- Providing rehabilitation information (exercise programs, vocational educational materials, job placement programs) to providers and patients;
- Addressing patient grievances and family concerns;
- Assisting transient patients in finding dialysis services.

Networks are a significant provider of information to facilities. Networks house and regularly distribute information to facilities regarding:

- Evidence-based medicine including clinical practice guidelines and care paths;
- Disaster preparedness;
- FDA alerts;

- Centers for Disease Control and Prevention guidelines and recommendations;
- Patient education materials;
- National ESRD CPM Project annual reports, highlight reports and supplemental reports.

Many Network staff are trained in conflict resolution and mediation and provide facilities with an accessible resource to discuss handling challenging patients. Many Networks house a library that contains patient education videos and materials that are available to facilities and patients on request.

All Networks convene meetings directed at bringing together facility personnel to discuss on-going and emerging clinical issues. Sites for these meetings are chosen based on accessibility and convenience in order to attract a large number of participants. These meetings may offer incentives such as continuing education credits. Meeting topics are determined regionally by a planning committee composed of all stakeholders with the goal of improving processes of care. Recent meeting topics have focused on:

- Patient safety and medical errors;
- Adequacy of dialysis;
- Vascular access;
- Managing anemia;
- Dealing with challenging patients.

5. Forum Initiatives Directed At Improving The Quality Of Care Dialysis Patients Receive

The Forum's role in improving the quality of care received by ESRD patients is through enhancing the effectiveness of the 18 Networks. Interventions by the Networks have led to a significant improvement in the percentage of patients receiving adequate dialysis as demonstrated by data from the national ESRD CPM Project cited above. Opportunities for improved dialysis adequacy continue to exist and all Networks will focus on this area for their 2000–2001 quality improvement projects. The standards for dialyzer reuse are specified in the Conditions of Coverage for Medicare-approved dialysis facilities and are enforced by state surveyors. The Conditions of Coverage currently in effect do not specify standards for dialysis facility staffing ratios and training.

The Forum has assumed a leadership role in identifying new initiatives that enhance the effectiveness of the Networks in improving patient care. The Forum's activities are driven by its strategic plan (Figure 2). Appendix 1 summarizes the 1999-2000 accomplishments of the Forum in each of the strategic plan domains. Appendix 2 summarizes the current activities of the Forum in each of the strategic plan domains. Some of the most significant activities include:

- Collaborating with the Renal Physicians Association and National Patient Safety Foundation in the development of a Patient Safety Committee to investigate and reduce medical errors in dialysis facilities;
- Designing a National Quality Improvement Project addressing vascular access;
- Participating on the Public Reporting and State Surveyor Committees addressing the public release of data;
- Assisting HCFA in the development of a patient orientation package to be distributed to each new ESRD beneficiary.
- Partnering with the Renal Physicians Association to rank and implement the NKF-DOQI guidelines at the provider level;
- Surveying Networks to report on renal transplant assessment activities;
- Participating in the Renal Physicians Association's development of "Shared Decision-Making in the Appropriate Initiation and Withdrawal from Dialysis" clinical practice guideline.

Conclusion

The increasing visibility and credibility of the Forum and the ESRD Networks in the national landscape are due, in large part, to their long-standing and unwavering advocacy for improved ESRD patient outcomes through the application of continuous quality improvement methodologies and the development of an appropriate data infrastructure. This advocacy is untainted by the agenda of any single professional constituency, and its success is limited only by the commitment that all stakeholders have to the process. Through their clearinghouse activities, the Forum and the ESRD Networks foster evidence-based medicine, increasing provider awareness of clinical practice guidelines and other literature that may improve the quality of patient care. Although opportunities for improvement continue to exist, the dramatic increase in the percentage of patient receiving adequate dialysis and achieving target hematocrit levels over the past 6 years demonstrates the ability of Networks to effect change. With the volunteer expertise that resides within the Medical Review Boards and an evolving powerful data infrastructure, the Networks are an invaluable resource that continuously brings the quality of patient care to a higher level.

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Appendix 1: Forum Accomplishments

GOALS	1999-2000 ACCOMPLISHMENTS
Provide Leadership	
Create Information Infrastructure	<ul style="list-style-type: none"> • Implemented Standardized Information Management System (SIMS) • Continued to develop and formalize United States Renal Data System (USRDS) relationship • Collaborated in the development and testing of a facility data system • Actively sought to communicate with the private sector industry
Expand Quality Measurement and Reporting	<ul style="list-style-type: none"> • Participated on National ESRD CPM Project committees and subcommittees • Merged the CPM and Core Indicators Projects • Disseminated and implemented the NKF-DOQI clinical practice guidelines • Participated in the “Shared Decision Making in the Initiation and Withdrawal of Dialysis” clinical practice guideline • Encouraged organizations, such as Council of American Kidney Societies, to actively seek and take the lead in a research venture with an academic medical center • Began to establish a relationship with the National Patient Safety Foundation and RPA in the development of a patient safety committee • Received HCFA contract to survey Networks on transplant data and referrals • Supported Networks 1 & 11 collaboration with RPA to prioritize clinical practice guidelines
Foster Evidence-Based Medicine	<ul style="list-style-type: none"> • Circulated CQI articles to MRB Chairs • Encouraged Forum representatives to speak at national meetings to update the community on the Forum's current activities and positions • Used Forum Clearinghouse to gather information
Enhance Patient Participation and Strengthen the Hand of Consumers	<ul style="list-style-type: none"> • Received HCFA contract to develop committee to recommend a standardized new patient packet

<p>Create Public-Private Partnerships</p>	<ul style="list-style-type: none"> • Developed CPM Initiative with HCFA, RPA, NKF • Supported the renal community's (RPA/ASN/FORUM) implementation of NKF-DOQI project • Maintained RPA relationship and share committee representation • Supported the Forum Clearinghouse as a partner with HCFA • Evaluated the need for & type of information applicable for public release • Explored private sector accreditation • Researched expanding state surveyor agency collaboration • Distributed Core Indicators and Anemia QIPs • Initiated and encouraged the growth of existing partnerships with dialysis chains • Established relationship with renal magazines to published Network accomplishments and projects
<p>Facilitate Health Professional Education</p>	<ul style="list-style-type: none"> • Held regular MRB chair meetings • Encouraged Forum representatives to speak at national meetings on behalf of Forum and Networks • Developed liaison with RPA and ASN • Pursued joint initiative with RPA to support "Teach the Teachers" program

Appendix 2: Current Forum Activities

GOALS	2000 CURRENT ACTIVITIES
Provide Leadership	
Create Information Infrastructure	<ul style="list-style-type: none"> • Pursue facility data system collaboration with HCFA • Developing and formalizing USRDS relationship • Exploring data collection of difficult patients • Final implementation of Standardized Information Management System
Expand Quality Measurement and Reporting	<ul style="list-style-type: none"> • Participating on national ESRD CPM Project committees and subcommittees • Encouraging Network level reporting in support of quality improvement • Participating in the development of a Patient Safety Committee with RPA • Pursuing liaison with National Patient Safety Foundation through the Patient Safety Committee • Revising the Medical Records Model • Surveying Networks on transplant data, referrals and outcomes
Foster Evidence-Based Medicine	<ul style="list-style-type: none"> • Circulating CQI articles to MRB Chairs • Encouraging Forum representatives to speak at national meetings to update the community on the Forum's current activities and positions • Using Forum Clearinghouse to gather information • Collaborate with RPA to research physician level measures using evidence-based medicine
Enhance Patient Participation and Strengthen the Hand of Consumers	<ul style="list-style-type: none"> • Participating on the New Patient Packet Committee to distribute uniform information to patients

<p>Create Public-Private Partnerships</p>	<ul style="list-style-type: none"> • Supporting Dr. William Owen's initiative to develop a "Modifying Errors Noted in Dialysis Trial" proposal • Maintaining RPA relationship and share committee representation • Supporting the Forum Clearinghouse as a partner with HCFA • Evaluating the need for & type of information applicable for public release • Expanding state surveyor agency collaboration • Initiate and encourage the growth of existing partnerships with dialysis chains • Providing representation on Robert Wood Johnson End of Life Committee • Providing representation on State Survey Committee and Public Reporting committee of HCFA
<p>Facilitate Health Professional Education</p>	<ul style="list-style-type: none"> • Holding regular MRB chair meetings • Encouraging Forum representatives to speak at national meetings on behalf of Forum and Networks • Developing liaison with RPA and ASN • Pursuing joint initiative with RPA to support "Teach the Teachers" program
<p>Facilitate Network Quality Improvement Projects (QIPs)</p>	<ul style="list-style-type: none"> • Standardizing QIP activities and distribute document describing the differences between outcomes research and quality improvement • Documenting the success of Network QIPs • Develop partnership with renal magazines to publish QIP abstracts and Network activities • Supporting Networks 1 & 11 Prioritization QIP in conjunction with RPA